

# THE ASSOCIATION BETWEEN PERCEIVED STIGMA TOWARDS TUBERCULOSIS AND THE IMPLEMENTATION OF DIAGNOSIS PROCEDURE ON TUBERCULOSIS SCREENING PROGRAM IN DENPASAR, BALI, INDONESIA

I.W.G. Artawan Eka Putra<sup>1,2\*</sup>, P.A.S. Astuti<sup>2</sup>, I.M.K. Duana<sup>2</sup>, I.K. Suarjana<sup>2</sup>, K.H. Mulyawan<sup>2</sup>, N.M.D. Kurniasari<sup>2</sup>, I.B.G. Ekaputra<sup>3</sup>, A. Probandari<sup>4</sup>, C.U. Wahyuni<sup>5</sup>

<sup>1</sup> Faculty of Public Health, Universitas Airlangga, Indonesia

<sup>2</sup> School of Public Health, Faculty of Medicine, Universitas Udayana, Indonesia

<sup>3</sup> Denpasar Health Office, Indonesia

<sup>4</sup> Department of Epidemiology, Faculty of Public Health, Universitas Airlangga, Indonesia

<sup>5</sup> Department of Public Health, Faculty of Medicine, Universitas Sebelas Maret, Indonesia

Email: \*gedartawan@unud.ac.id

**Abstract:** The major issue of Tuberculosis (TB) control program in Indonesia including Bali is the low cases detection rate (32%). An intensive presumptive TB finding through screening program and then followed by diagnosis procedure is important to conduct. Meanwhile, perceived stigma is a social determinant of health that strongly associated to health-seeking behaviour. This study aimed to assess the association of perceived stigma towards TB to diagnosis procedure implementation among presumptive TB cases screened from diabetes mellitus (DM) patients. This was an operational research during the TB screening program among DM patients. The samples were collected consecutively from January until March 2016 at 11 public health centres (PHC) in Denpasar City, Bali Province. Data were collected via interview using structured questionnaire. Logistic regression was used for statistical testing. During 3 months implementation of screening program, there were 567 DM patients screened, 342 of them were presumptive TB cases and were recommended to follow TB diagnosis procedures. There were only 87(25,4%) who followed the procedure and 255 (74,6%) refused to participate. The refusal to diagnosis procedure was associated to the TB stigma (OR=1.7; 95%CI: 1.03-2.9). Meanwhile, perceived stigma towards TB was associated to the lack knowledge of TB (OR=2.0; 95%CI: 1.3-3.2) and the lack of family support (OR=1.8; 95%CI: 1.1-2.7). The diagnosis procedure coverage among presumptive TB cases screened from DM patient was still low. The perceived stigma towards TB is contributed to the high proportion of presumptive TB cases who did not follow the diagnosis procedure. Therefore, a comprehensive education to increase public awareness and support to the TB program are necessary.

**Keywords:** Tuberculosis case findings, perceived stigma, diagnosis procedure, screening program

## Introduction

Indonesia has a high burden of Tuberculosis (TB). Based on The National TB Prevalence Survey, the TB prevalence rate in Indonesia was 660 per 100.000 population. TB global report estimates that the incidence rate of TB in Indonesia in 2015 was 395 per 100.000 population. Meanwhile, the national cases notification rate (CNR) in 2015 was only 135 per 100.000 population. There is a big gap between incidence and notification rate. This data also showed the lack of national cases detection rate (CDR), which was only 32%. The CNR of TB in Bali province was lower than national rate, it was 70 per 100.000 population in 2015. The CDR in Bali also lower compare to that in national, which was only 21%. It means there was only 21% incidence of TB in the Balinese population that were notified and treated (National Institute of Health Research and Development - NIHRD, 2015; WHO, 2015; Health Office Of Bali Province, 2016).

A TB case finding, which followed to prompt treatment, is very important to end TB transmission. Passive cases finding is not adequate to find TB cases in the population. It should be enhanced into an active cases finding through screening program, one of them is to the high-risk population such as diabetes mellitus (Raviglione,

2010). DM weakens the body's immune responses and thus can increase the risk for TB infection (Creswell *et al.*, 2011). Since 2015, NTP initiates the TB screening program to DM patient. In 2016, The Denpasar Health Office had piloting an active TB case finding program through TB screening program among DM patients. All DM patients should be screened for TB using symptoms, sign identification and chest X-ray examination. The presumptive TB cases found during screening program should follow diagnosis procedure for confirmation. (Ministry of Health Republic of Indonesia, 2015).

The success of an active TB cases finding through this program is depend on the participation of presumptive TB cases who follow the diagnosis procedure. One of the main determinants of health-seeking behaviour is perceived stigma. Perceived stigma is a perceived among people regarding social exclusion in population which related to certain diseases. Social exclusion is one of social determinant of health that have major consequent in health inequity (Hatzenbuehler, Phelan and Link, 2013; Craig *et al.*, 2017). Most presumptive TB cases (51.3%) perceived that other people would consider them inferior if they have TB (Abebe *et al.*, 2010).

This study aimed to assess perceived stigma towards TB among DM patients who follow TB screening program and to analyse the association between perceived stigma towards the implementation of TB diagnosis procedure.

## **Methods**

### ***Design***

This was an operational research of the implementation of TB screening program among DM patients. The study used cross-sectional design.

### ***Study setting***

Denpasar is the capital city of Bali Province, Indonesia. The population in Denpasar in 2015 was 880,600 with the sex ratio of 104,5%. Denpasar is the most populated area in Bali Province with population density of 6,891.5 people per km<sup>2</sup>. Denpasar has 11 public health centres and 4 state hospitals. Based on National Health Research, the prevalence of DM in Denpasar was 2.8%. Denpasar also have the highest number of presumptive TB who were examined and there were more than 4,500 presumptive TB in a year (Denpasar Health Office, 2016). The NTP in Indonesia uses the WHO-recommendation of Directly Observed Therapy Short course (DOTS) strategy. The management of presumptive TB cases is a priority because normally 10% of them will confirm smear positive. A case treatment and the monitoring and reporting system are following WHO guidelines (Ministry of Health Republic of Indonesia, 2014).

### ***Population and sample***

The study population was presumptive TB that screened from DM patients who visited public health centres (PHC) in Denpasar City from January until March 2016. A presumptive TB was a DM patient who had minimum one of TB symptoms or had an abnormality in lung or pleura based on chest X-ray. Sample was selected consecutively from January until March 2016 in 11 public health centres (PHC) in Denpasar City, Bali Province.

### ***Variable, data collection and analysis***

Perceived stigma towards TB is a belief when presumptive TB will receive social exclusion if they are diagnosed as TB. The implementation of diagnosis procedures is procedures that should be followed by presumptive TB for TB confirmation. TB confirmation was used sputum smear examination. Knowledge regarding TB is knowledge of presumptive TB regarding the determinant, mode of transmission, symptom, mode of prevention, susceptibility and the importance of TB early diagnosis. Family support is the support of presumptive TB's

family given to subjects to follow TB diagnosis procedure, which includes some supports on transportation, financial and motivation. The data of perceived stigma, knowledge regarding TB and family support were collected via interview using structured questionnaire. The data of diagnosis procedure implementation were checked at smear results slip. The association of perceived stigma towards TB and diagnosis procedure implementation were identified using logistic regression.

### Results

Based on the implementation of TB screening program among DM patient, we have 567 DM patients visited PHCs in the period of January to March 2016. A 342 of them have symptoms or shown an abnormality on the chest X-ray examination result. We identified them as presumptive TB that should follow diagnosis procedure. Among 342 presumptive TB, only 87 or 25,4% following diagnosis procedure (Figure 1).

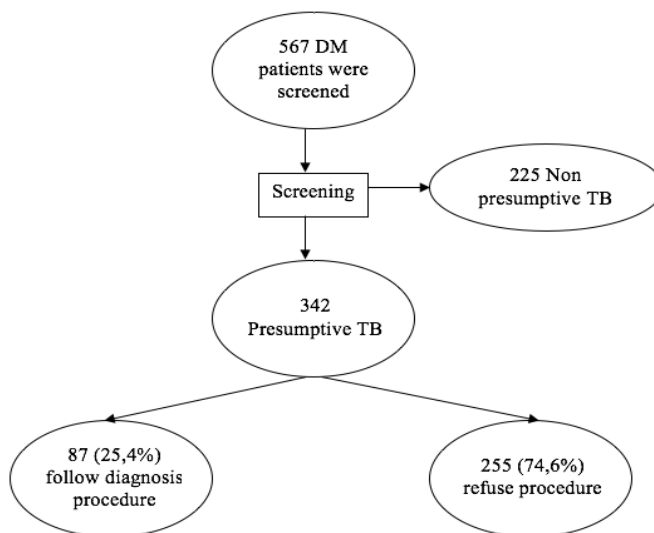


Figure 1. Scheme of Screening And Diagnosis Procedure

The subjects' characteristics are shown in table 1. The mean of age of subjects who followed diagnosis procedure was 60.8 years old and subjects who did not follow diagnosis procedure was 61.8 years old. The proportion of male among those who followed diagnosis procedure was 59.8% and among those who did not follow diagnosis procedure was 47.1%. There were 59.8% subjects who followed diagnosis procedure have educational background higher than junior high school and 49.0% were among those who did following diagnosis procedure. Most of them in both groups were still actively work and have health insurance. There were no difference of the subject's characteristics between presumptive TB who followed diagnosis procedure and those who did not follow the diagnosis procedure (Table 1).

Table 1. The Subjects Characteristic

Variable	Following procedure		Overall
	Yes (n=87)	No (n=255)	
Age (year) mean±SD	60.8±8.7	61.8±8.8	61.5±8.8
Sex, male	52 (59.8)	120 (47.1)	172 (50.3)
Education, >Junior High School	52 (59.8)	125 (49.0)	177 (51.8)
Employment			
Active work	61(70.1)	138(65.1)	229(66.4)
Retirement	26(29.9)	87(34.9)	113(33.6)
Have health insurance	84(96.6)	247(96.9)	331(96.8)

The association between perceived stigma towards TB, knowledge regarding TB and family support to follow the diagnosis procedure of presumptive TB screened from DM patients are shown in table 2. There were 150 of 342 presumptive TB (43.9%) believe that they will receive social exclusion if they were diagnosed as TB. There were 30.2% subjects followed diagnosis procedure among presumptive TB with no perceived stigma towards TB, meanwhile only 19.3% subjects followed diagnosis procedure amongpresumptive TB with perceive stigma towards TB. Perceived stigma towards TBwas associated to the succeeded of presumptive TB to follow diagnosis procedure with adjusted odds ratio (AOR) 1.7 and 95% CI: 1.03-2.9. The knowledge regarding TB and family support were not directly associated to the implementation of diagnosis procedure of presumptive TB (Table 2).

Table 2. The Association Between Perceived Stigma Towards TB, Knowledge Regarding TB and Family Support to Follow the Diagnosis Procedure by Presumptive TB Screened fromDM Patients

Variable	Follow procedure		Simple logistic OR (95%CI)	p value	Multiple logistic AOR (95%CI)	p value
	Yes (n=87)	No (n=255)				
Perceive stigma towards TB						
No	58(30.2)	134 (69.8)	1.8 (1.1-3.0)	0.023	1.7 (1.03-2.9)	0.039
Yes	29 (19.3)	121 (80.7)	ref			
Knowledge regarding TB						
Good	47(27.8)	122(72.2)	1.3 (0.8-2.1)	0.310	1.2 (0.7-2.0)	0.460
Lack	40(23.1)	133(76.9)	ref			
Family support						
Good	41(27.5)	108(72.5)	1.2 (0.7-2.0)	0.438	1.2 (0.7-1.9)	0.529
Lack	46(23.8)	147(76.2)	ref			

The association between knowledge regarding TB and family support to the perceived stigma towards TB are shown in Table 3. Among presumptive TB with lack knowledge regarding TB, 51.5% have perceive stigma towards TB, meanwhile among presumptive TB with good knowledge regarding TB, 36.1% have perceived stigma towards TB. Knowledge regarding TB was associated to the perceive stigma towards TB with AOR2.0 and 95% CI: 1.3-3.2. Among presumptive TB with lack family support, 48.7% have perceive stigma towards TB while among presumptive with good family support 37.6% have perceive stigma towards TB. Knowledge regarding TB was associated to the perceive stigma towards TB with AOR 1.8 and 95% CI: 1.1-2.7 (Table 3).

Table 3. The Association Between Knowledge Regarding TB and Family Support to The Perceived Stigma Towards TB

Variable	Perceived stigma towards TB		Simple logistic OR (95%CI)	p value	Multiple logistic AOR (95%CI)	p value
	Yes (n=150)	No (n=192)				
Knowledge regarding TB						
Lack	89(51.5)	84(48.5)	1.9 (1.2-2.9)	0.004	2.0 (1.3-3.2)	0.002
Good	61(36.1)	108(63.9)	ref			
Family support						
Lack	94(48.7)	99(51.3)	1.6 (1.02-2.4)	0.040	1.8 (1.1-2.7)	0.014
Good	56(37.6)	93(62.4)	ref			

### Discussion

This study showed that many of the presumptive TB subjects believed they would have received social exclusion if they had TB. A study among presumptive TB in a rural community in Southwest Ethiopia also showed that perceived stigma towards TB was still high in population. A 51.3% presumptive TB perceived that their community would consider them inferior if they had TB (Abebe *et al.*, 2010). It is similar compare to this result, which found 43.9% people still have perceived stigma. This fact showed that stigma towards TB are still exist in the populations even in urban area such as in Denpasar City. In the other areas (rural) of Bali, the perceived stigma towards TB might be higher than this finding. Stigma towards TB should be solved integrally in TB control program. An education for presumptive TB cases should include psychological intervention to reduce perceived stigma (Tola *et al.*, 2016). A community intervention is also essential for educating people in the population such community leaders, public figures, religious leaders and non-government organizations. This is important because those figures are considered role models who have power to influence, educate and reduce the stigma towards TB in the community (World Health Organization, 2008; Arshad *et al.*, 2014).

The perceived stigma towards TB was associated to the presumptive TB who did not following diagnosis procedure. This finding has proven the consequence of TB stigma. Perceived stigma inhibits social interaction. One who keeps a secret of stigmatized disease will feel isolated. Therefore, the presumptive TB will disobey any advices from doctor or other health officer. Perceived stigma is a barrier to access health facilities. In term of health services on TB, perceived stigma lead to the delay of diagnosis and the incompletion of the TB treatment (Aryal *et al.*, 2012; Anand *et al.*, 2014; Sharp *et al.*, 2015). A qualitative study exploring the perceived stigma towards TB and discrimination found perceive stigma was strongly associated to the specific sociocultural context. Interventions to reduce stigma should adopt specific socio-cultural contexts. The social stigma will cause self-discrimination. Self-discrimination is withdrawing him or herself from social relationships because they perceived unacceptable in the community (Baral, Karki and Newell, 2007). The educational and psychological interventions are important for people with presumptive TB, and to their family and the community are necessary to reduce stigma toward TB.

This study also found that perceived stigma towards TB was associated to the knowledge regarding TB and to the family support. This finding implicates that NTP should consider a comprehensive education to presumptive TB in a screening setting. The education is not only for the presumptive and people with TB but also to their family. An education to the community is also important particularly to increase their knowledge the determinant, mode of transmission, symptom, mode of prevention, susceptibility, the important of TB early diagnosis and explain that TB is a curable disease. This results provides important information to the TB control program about how to reduce perceived stigma towards TB.

NTP should enhance the coverage of TB health care services and provide further information to increase awareness of the community regarding TB. Therefore, TB officers and physicians in PHC should be capable to

identify particular problem faced by presumptive TB, including perceived stigma towards TB. When health officers conduct anamnesis or interviewing patients, they should ask about the perceived of presumptive if one had TB. They need a reliable instrument to identify perceived stigma towards TB. It will be very useful to plan proper education and knowledge to reduce the perceived stigma (Somma *et al.*, 2008; Arcêncio *et al.*, 2014). Similar finding is found in several studies regarding TB screening, case finding and consequence of TB stigma. A comprehensive health education to raise awareness and reduce the perceived stigma towards TB is main recommendation in those studies (Kidd *et al.*, 2009; Arcêncio *et al.*, 2014; Cremers *et al.*, 2015; Craig *et al.*, 2017).

The study limitations were regarding the measuring of perceived stigma. The instrument that used is limited, it only asked about social exclusion in daily activity. The questions were not included sociocultural activity in the community as the important aspect of perceived stigma. In terms of study period, this study also observe presumptive TB in limited time (only from 3 months of TB screening program implementations). The data from a year period should have more reliable result findings.

### **Conclusions**

The major problem of TB screening program among DM patient is the low of presumptive TB who follow diagnosis procedure. Almost half of presumptive TB in urban area of Bali perceived stigma towards TB. The perceived stigma towards TB was associated to the low of presumptive TB follow diagnosis procedure. The lack knowledge regarding TB and family support were associated to perceived stigma towards TB. A comprehensive educational and physiological intervention are important to reduce perceived stigma towards TB. Health education should be focus on the determinant, mode of transmission, symptom, mode of prevention, susceptibility, the important of TB early diagnosis and TB is a curable disease. Community and family based TB control program to increase family support are essential.

### **Acknowledgements**

This research was funded by a grant from The Global Fund – NTP. The authors would like to thank to The Global Fund and National TB control Program (NTP) Ministry of Health of the Republic of Indonesia and the Tuberculosis Operational Research Group of Indonesia for their support and supervision on the research implementation. The authors would like to thank all respondents who kindly consented to participate in this study. We sincerely thank TB officers in Denpasar City for their support and provision of TB related epidemiological information. The author also would like to thank to Lembaga Pengelola Dana Pendidikan (LPDP) (Indonesian Education Scholarship) for the support on this publication and funding the author attending the 3<sup>rd</sup> International Conference on Public Health (ICOPH).

### **References**

- Abebe, G., Deribew, A., Apers, L., Woldemichael, K., Shiffa, J., Abdissa, A., Deribie, F., Jira, C., Bezabih, M., Aseffa, A. and Colebunders, R. (2010) 'Knowledge, Health Seeking Behavior and Perceived Stigma towards Tuberculosis among Tuberculosis Suspects in a Rural Community in Southwest Ethiopia', *PLoS one*, 5(10), pp. 1–7. doi: 10.1371/journal.pone.0013339.
- Anand, T., Kumar, D. A., Sharma, N., Saha, R., Krishnamurthy, L., Singh, S. V and Ingle, G. K. (2014) 'Perception of stigma towards TB among patients on DOTS & patients attending general OPD in Delhi.', *The Indian journal of tuberculosis*, 61(1), pp. 35–42. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/24640343> (Accessed: 9 May 2017).
- Arcêncio, R. A., Crispim, J. de A., Touse, M. M., Popolin, M. P., Rodrigues, L. B. B., Freitas, I. M. de, Yamamura, M. and Neto, M. S. (2014) 'Preliminary validation of an instrument to assess social support and tuberculosis stigma in patients' families', *PHA*, 4(3), pp. 195–200. doi: 10.5588/pha.13.0095.

- Arshad, A., Salam, R. A., Lassi, Z. S., Das, J. K., Naqvi, I. and Bhutta, Z. A. (2014) 'Community based interventions for the prevention and control of tuberculosis', *Infectious Diseases of Poverty* 2014, 3(14), pp. 1–10.
- Aryal, S., Badhu, A., S. P., A. B., P. K. and Khatiwada P, Khatiwada P, G. A. (2012) 'Stigma Related to Tuberculosis Among Patients Attending DOTS Clinics of Dharan Municipality', *Kathmandu Univ Med J*, 37(1), pp. 48–52. Available at: <http://www.kumj.com.np/issue/37/48-52.pdf> (Accessed: 6 June 2017).
- Baral, S. C., Karki, D. K. and Newell, J. N. (2007) 'Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study', *BMC Public Health*, 7(211), pp. 1–10. doi: 10.1186/1471-2458-7-211.
- Craig, G. M., Daftary, A., Engel, N., O 'driscoll, S. and Ioannaki, A. (2017) 'Tuberculosis stigma as a social determinant of health: a systematic mapping review of research in low incidence countries', *International Journal of Infectious Diseases*, 56, pp. 90–100. doi: 10.1016/j.ijid.2016.10.011.
- Cremers, A. L., De Laat, M. M., Kapata, N., Gerrets, R., Klipstein-Grobusch, K. and Grobusch, M. P. (2015) 'Assessing the consequences of stigma for tuberculosis patients in urban Zambia', *PLoS ONE*, 10(3), pp. 1–16. doi: 10.1371/journal.pone.0119861.
- Creswell, J., Raviglione, M., Yew, W. W. and Migliori, G. B. (2011) 'Tuberculosis and noncommunicable diseases: neglected links and missed opportunities', *Euro Respir J*, 37(7), pp. 1269–1282. doi: 10.1183/09031936.00084310.
- Denpasar Health Office (2016) *Denpasar Health Profile 2015*. Denpasar.
- Hatzenbuehler, M. L., Phelan, J. C. and Link, B. G. (2013) 'Stigma as a Fundamental Cause of Population Health Inequalities', *Am J Public Health*, 103(10), pp. 813–821. doi: 10.2105/AJPH.
- Health Office Of Bali Province (2016) *Health Profile Of Bali Province 2015*. Denpasar.
- Kidd, R., Clay, S., Belemu, S., Bond, V., Chonta, M. and Chipso Chiya (2009) *Understanding and challenging TB stigma Toolkit for action*. Available at: [http://targets.lshtm.ac.uk/resources/Publications/TB\\_and\\_Stigma\\_Eng2.pdf](http://targets.lshtm.ac.uk/resources/Publications/TB_and_Stigma_Eng2.pdf) (Accessed: 6 June 2017).
- Ministry of Health Republic of Indonesia (2014) *National Guidelines of Tuberculosis Control*. Edited by T. N. Dinihari and V. Siagian. Jakarta.
- Ministry of Health Republic of Indonesia (2015) *Technical Guidelines of Tuberculosis Case Finding On Diabetes Mellitus Patients*. Jakarta.
- National Institute of Health Research and Development - NIHRD (2015) *Indonesian Tuberculosis Prevalence Survey Report 2014*. Jakarta.
- Raviglione, M. C. (2010) *Tuberculosis Fourth Edition The Essentials*. Fourth, Informa Healthcare USA, Inc. Fourth. Edited by M. C. Raviglione. New York: Informa Healthcare USA, Inc.
- Sharp, M., Fear, N. T., Rona, R. J., Wessely, S., Greenberg, N., Jones, N. and Goodwin, L. (2015) 'Stigma as a Barrier to Seeking Health Care Among Military Personnel With Mental Health Problems', *Epidemiologic Reviews*, 37, pp. 144–162. doi: 10.1093/epirev/mxu012.
- Somma, D., Thomas, B. E., Karim, F., Kemp, J., Arias, N., Auer, C., Gosoni, G. D., Abouihia, A., Weiss, M. G. and Weiss, M. (2008) 'Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia', *INT J TUBERC LUNG DIS*, 12(7), pp. 856–866. Available at: <http://www.who.int/tdr/publications/documents/tb-related-stigma.pdf> (Accessed: 6 June 2017).
- Tola, H. H., Shojaeizadeh, D., Tol, A., Garmaroudi, G., Yekaninejad, M. S., Kebede, A., Ejeta, L. T., Kassa, D. and Klinkenberg, E. (2016) 'Psychological and Educational Intervention to Improve Tuberculosis Treatment Adherence in Ethiopia Based on Health Belief Model : A Cluster Randomized Control Trial', *PloS one*, 11(5), pp. 1–15. doi: 10.1371/journal.pone.0155147.
- WHO (2015) *Global tuberculosis report 2015*. Geneva.
- World Health Organization (2008) *Community involvement in tuberculosis care and prevention: Towards partner for health*, *World Health*. doi: WHO/HTM/TB/2008.397.